

**New York City Department for the Aging**  
**Post Event Summary Report**  
**For Officially Designated White House Conference on Aging Event**

**Name of Event:** Caregiver Conference  
**Date of Event:** Friday, June 24, 2005  
**Location of Event:** The City College of New York (Harlem)  
**Number of Persons attending:** 200  
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**Background:** For twenty years, the New York City Department for the Aging has hosted its annual Mayoral Conference on Alzheimer's disease, responding to the needs of New York City's 1.3 million seniors and their caregivers. While this educational event now attracts nearly 1000 attendees, more information is needed for harder to reach populations, especially minorities groups. In an effort to respond to the needs of the largely African-American community of Harlem, the New York City Department for the Aging hosted a caregiver conference at the City College of New York for family caregivers of seniors with Alzheimer's disease and grandparents raising grandchildren. This all day event provided a moving keynote address and two sets of workshops tracks. Workshops on community options (addressing issues of support groups, home delivered meals, transportation, adult day services, respite, homecare, insurance options, housing, and permanency planning) were offered. Additionally, a future planning workshop was conducted for grandparents raising grandchildren and a health and aging workshop was given for Alzheimer's families. Policy roundtables for each group were held to prioritize salient issues facing seniors which should be addressed at the upcoming White House Conference on Aging. Priority areas were voted on and prioritized by each group. The top three priorities from the two groups (family caregivers of seniors with Alzheimer's disease and grandparents raising grandchildren) are described in the following summary report:

**I. FAMILY CAREGIVERS OF SENIORS WITH ALZHEIMER'S DISEASE**

**Priority Issue #1: HOUSING**

- Seniors require special housing to meet their specific needs
  - Accessibility (ramps, working elevators)
  - Safety (adequate lighting, safety rails—especially in hallways and bathrooms)
  - Assistance (help with travel and getting to activities)

- Seniors are facing homelessness because landlords want them out
  - Senior evictions due to special needs listed above
  - Seniors priced out of affordable housing

**Barriers:**

- No existing legal protection for seniors' housing
- Co-op regulations prevent seniors from making needed home adaptations

**Proposed Solutions:**

- Create housing to meet seniors' physical and financial needs
  - Universal design for new construction
- Mandate the use of adaptive products including
  - Raised toilets
  - Easy to open windows
  - Wheelchair accessibility
- Create housing legislation to protect seniors
  - Prevent evictions
  - Protect renters
- Legislate co-op guideline modification to address senior housing needs
  - Exempt households age 65 and over from laws preventing them from installing adaptive devices and making necessary home alterations

**Priority Issue #2: MEDICAL NEEDS**

- Government programs need modifications to meet financial, physical, and psychosocial needs of seniors
- Service providers in the medical community (hospitals, clinics) often display a lack of respect and understanding of seniors' physical and psychological needs
- Lack of medically-related services for specific populations within the senior community
  - Age-related mental health services
  - Services for persons with Alzheimer's disease and other dementias
  - Services for the homebound and physically impaired
  - Services for the visually and hearing impaired

**Barriers:**

- Complication of government mandate involving HMO participation with Medicare
  - HMOs are often reluctant to pay out for needed senior services

- Medicare Part D
  - Application process is difficult to negotiate
  - Application process does not consider the visual needs of the elderly (no available Braille or large print application materials)

**Proposed Solutions:**

- Evaluate health care programs
  - Review Medicare and Medicaid systems (especially Medicare Part D) and start all over again as needed
  - Set up a system of checks and balances to see where/how monies to HMOs are being spent
- Recognize and address the mental health needs of seniors with specialized services in
  - Depression and loneliness
  - Grief and bereavement counseling (and logistical issues of transportation to cemeteries )

**Priority #3: LONG TERM CARE PROGRAMS**

- Not enough is being done to help seniors remain independent in the community despite growing dependency needs

**Barriers:**

- Lack of culturally competent programs
- Lack of funding for long term care programs

**Proposed Solutions:**

- Investigate growing diversity in New York City to look at the housing and long term care needs of different cultures
- Appoint a commission to research and examine how to meet the needs of different groups
  - Ethnic/racial
  - Socioeconomic
  - Religious
- Increase funding for respite care
  - Pass Lifespan Respite bill
- Increase funding for Title III-E programs
- Increase funding and locations of adult day programs

## **II. GRANDPARENTS RAISING GRANDCHILDREN**

### **Priority #1: FINANCIAL ASSISTANCE**

- Grandparent caregivers are in need of financial assistance

#### **Barriers:**

- Grandparent caregivers frequently receive misinformation when applying for services
- Applications for public assistance and subsidized guardianship vary from state to state
- TANF payments do not meet the needs of grandparent families
- Grandparents have inadequate knowledge about available grants and often have difficulty completing the complex application forms
- Kinship caregivers do not have the funds to pay for needed services (legal services, health care, respite)
- Grandparents often neglect their own health to provide for their grandchildren's health care needs

#### **Proposed Solutions:**

- Pass the Subsidized Guardianship bill
  - Expand and increase subsidized guardianship for children who are not in foster care
- Provide additional training for staff in social services
- Increase "child only" grants
- Increase access to low cost childcare
- Ensure access for all family members to health care so grandparents will not need to choose between their own health and their grandchildren's needs
- Establish a mechanism to provide grandparent caregivers with free or subsidized legal assistance

### **Priority #2: HOUSING**

- Grandparents raising grandchildren lack affordable housing

#### **Barriers:**

- Overall lack of affordable housing in New York City
- Grandparents are often ineligible for housing due to age limitations
  - Current regulations bar anyone under age 60 from senior housing

#### **Proposed Solutions:**

- Provide funding to develop more housing with specialized services for grandparents and grandchildren
- Remove age limitations for grandparents who need grandparent housing
- Train housing staff on grandparent issues

**Priority Issue #3: SYSTEM NAVIGATION**

- Grandparents have difficulty navigating systems to access programs and assistance

**Barriers:**

- Grandparents often have to go from place to place to receive needed services
- Kinship caregivers do not have access to needed services
- Grandparents often lack information about available services
- Grandparent caregivers are often unable to navigate the complex maze of services

**Proposed Solutions:**

- Create navigator “one stop” programs in each state
  - Create a single point of entry through which kinship care families can be guided through the maze of health, legal, and human service agencies and programs
- Provide funding for one stop (navigators) programs
- Expand collaborative efforts between aging, child welfare, mental health, social service, and legal systems
- Develop national and local task forces to collaborate on kinship issues